Appendix B:

Primary Data Sources

Although carefully edited, analyzed, and reported, the statistics included in *The Health of Washington State* are essentially raw data. To translate these data into information for action (that is, developing appropriate and well-informed policy and public health interventions), readers need to perform at least three steps in addition to reading the document:

1) Identify the indicator(s) in the disease continuum which are represented in *The Health of Washington State.*

2) Become familiar with the sources of information used to describe those indicators.

3) Compare the data in this document with other sources of information.

Through this process, readers will be able to synthesize and interpret the data included here This will lead to the most effective and efficient use of public health resources and result in the greatest benefit to the residents of Washington.
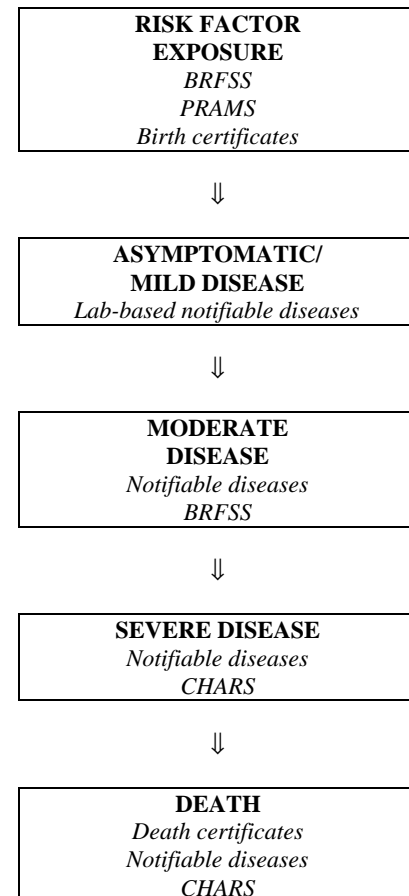
Continuum of Disease and Indicators

For every disease/health condition, there is a continuum of events beginning with exposure to the causal agent or practice of a risky behavior and ending in the development of clinical disease leading to hospitalization or death of the individual (see illustration in the next column). Each point along the continuum can be measured by an indicator. These indicators can provide very different perspectives on the disease/health condition and its impact on the community.

Different sources of data may provide the best information at different stages of this continuum. There are no hard and fast rule regarding best sources of data; this illustration is provided only as a means to understand the concept.

Ideally, with unlimited resources, data would be available for each point in the continuum; however, this rarely is the case (particularly when using existing data as was done with *The Health of Washington State*).

CONTINUUM OF DISEASE
and
Best source of data

RISK FACTOR EXPOSURE
BRFSS
PRAMS
Birth certificates

⇓

ASYMPTOMATIC/ MILD DISEASE
Lab-based notifiable diseases

⇓

MODERATE DISEASE
Notifiable diseases
BRFSS

⇓

SEVERE DISEASE
Notifiable diseases
CHARS

⇓

DEATH
Death certificates
Notifiable diseases
CHARS

Comparison with other Data Sources

To make the most appropriate decisions, readers should compare data in this document with other available information. This includes other measures of impact of the disease (e.g., incidence, prevalence, hospitalizations, hospital costs, mortality) as well as other sources of data (e.g., national data, data from other states, and data from special studies). Readers should also compare findings on different indicators to help put the impact of a particular disease/health condition into perspective. Such cross-comparisons will enable readers to get the big

picture of the health of Washington state residents and understand the many diseases/health conditions necessitating the use of public and private health resources

Sources of Data

Numerous sources of data are available at the local, state, and national levels to support public health planning and assessment activities. These sources are maintained by different offices and agencies and are developed for a variety of reasons. As a result, they vary in quality and appropriateness for monitoring public health problems and the impact of interventions.

Over 30 different sources of information were used to develop *The Health of Washington State*. The outlines below provide brief descriptions of the seven major Washington state sources of data that were used:

- Death certificate system
- Birth certificate system
- Behavioral Risk Factor Surveillance System (BRFSS)
- Notifiable Disease Surveillance
- Comprehensive Hospital Abstract Reporting System (CHARS)
- Washington State Cancer Registry
- Pregnancy Risk Assessment Monitoring System (PRAMS)

Each description includes the purpose for which the data were originally collected, the population covered, the source of the data, caveats about the data, and the best uses of the data. Readers are encouraged to review this information carefully so they fully understand the strengths and limitations of the data sources and know how to interpret data from these sources.

Death Certificate System - Center for Health Statistics

Description of the System
· **Purpose:** To provide public health information; to establish legal benefits
· **Coverage:** All deaths in Washington State - for residents and occurrences
· **Years:** Paper records: 1907-present; Automated records: 1968 - present

· **Data Elements** (examples): age, sex, race/ethnicity, date of death, cause of death, place of residence, place of occurrence, zip code, occupation, education
· **Reporting System:** Demographic information is gathered by the funeral director; cause of death is reported by the attending physician or the coroner/medical examiner. Certificate is filed with the local health jurisdiction, retained for about 60 days for local issuance purposes, then filed with DOH.
· **Criteria for Medical Certification of Death:** International Classification of Disease, Ninth Revision (ICD-9), World Health Organization
· **Data Quality Procedures:** Instruction manuals are provided to physicians, coroners, etc.. Edits and a physician query system are used to check for internal consistency and logic/completeness of cause of death.

Caveats
· Death rates may underestimate the magnitude of certain public health problems for deaths that may be under-reported due to social stigma (e.g., AIDS, suicide).
· The number of deaths in certain racial subgroups (e.g., Asians, Native Americans) may be underestimated due to the misclassification of deaths for some persons in those groups as white.
· Differences between counties could reflect cause of death reporting tendencies by local physicians, coroners, or medical examiners.

Best Uses
· Represent entire population of the state
· Examine trends in mortality over time
· Compare local, state, national, and international trends with comparable data
· Compare population subgroups (e.g, race, age, sex, occupation)
· Investigate spatial patterns and correlates (e.g., social, environmental factors)
· Support public health surveillance in a cost-efficient manner

Birth Certificate System - Center for Health Statistics

Description of the System

· **Purpose:** To provide public health information about births and newborns; to establish legal rights associated with birth, paternity, and adoption

· **Coverage:** All births in Washington State - for residents and occurrences

· **Years:** Paper records: 1907-1991; Automated records: 1968-present

· **Data Elements (examples):** date of birth, sex, race/ethnicity, place of residence, place of birth, zip code, education, prenatal care, smoking, method of delivery, birth weight, congenital anomalies, medical risks, obstetric procedures, complications

· **Reporting System:** The Electronic Birth Certificate (EBC) system was implemented in 1992 which enabled hospitals and birth attendants to enter legal and confidential patient information required for the birth certificate directly into the automated information system. This system replaced paper copies.

· **Source of Information:** Medical records; Worksheets completed by patients

· **Data Quality Procedures:** Instruction manuals and training in the completion of the birth certificate and the use of the electronic system are given to hospital staff and birth attendants. Data quality procedures include: range of value checks, internal consistency edits, mandatory data entry fields, and checks for consistency in trends over time. Hospitals and birth attendants are queried about possible errors or incomplete information. Formal affidavits are required to change the record for paternities, adoptions, or corrections.

Caveats

· Health risk behavior during pregnancy (e.g., alcohol or tobacco use) is likely to be underestimated since this information is self-reported.

· Differences between counties in adverse birth outcomes could reflect incomplete extraction of information from medical records by some hospitals.

· Prenatal care may be under-reported if hospital staff are unfamiliar with a patient's history, which may be more common for some population subgroups.

Best Uses

· Provide information on all births in the population

· Examine trends in natality over time

· Compare local, state, national, and international trends with comparable data

· Compare population subgroups (e.g., race, age of mother)

· Combine with induced abortion data to produce pregnancy statistics

· Use as the denominator for infant mortality statistics

· Investigate factors that affect birth outcomes

Behavioral Risk Factor Surveillance System (BRFSS) - Center for Health Statistics

Description of the System

· **Purpose:** To provide indicators of health risk behavior, preventive practices, attitudes, and health care use and access in the population

· **Coverage:** Adults in households with telephones; sample size = 3,348 in 1995

· **Years:** 1987-present

· **Data Elements (examples):** health-risk behaviors (smoking, physical inactivity, nutrition); use of preventive services (cancer screening); use of health care; attitudes about health-related behavior; socio-demographics (age, income)

· **Reporting System:** Data are gathered from a randomly selected sample of adults living in households with telephones. Interviews are conducted in English by a survey research firm following survey administration protocols established by CDC. The questionnaire includes core questions used by all states and questions on topics of specific interest to Washington State.

· **Data Quality Procedures:** Survey administration procedures (e.g., call-backs to difficult-to-reach households) are used to improve the representativeness of the sample, efforts are made to achieve response rates recommended by CDC, and computer-assisted interviewing is used to minimize errors by interviewers. CDC pretests core questions and optional modules for validity. Interviewers are

trained professionally, and calls are monitored regularly.

Caveats:
· BRFSS may under-represent the poorer and more mobile portions of the population since they are less likely to live in homes with telephones.
· BRFSS does not represent persons who do not speak English.
· BRFSS does not represent persons who live in institutions.
· Characteristics of persons who refuse to participate are unknown.
· Health risk behavior may be underestimated since it is self-reported behavior subject to social acceptability norms.
· Use of preventive services may be underestimated due to recall error.
· Separate analyses of subpopulations that are too small (e.g., racial/ethnic groups, some counties) may not be possible with the statewide sample.

Best Uses
· Provide estimates of the prevalence of health risk behaviors, use of preventive services, use of and access to health care, and selected attitudes
· Examine trends in risk behavior, use of preventive services, etc.
· Compare local (large counties or groups), state, and national BRFSS data
· Investigate correlates of health risk behavior, etc. and compare subgroups
· Identify profiles of persons engaging in high risk behaviors

Notifiable Diseases

Description of the System
· **Purpose:** To monitor the incidence of selected diseases/health conditions and characterize populations at high risk for those diseases/conditions

· **Coverage:** All residents of Washington State
· **Years:** Vary depending on disease/health condition
· **Key Data Elements:** Age, sex, race/ethnicity, residence
· **Reporting System:** Health care providers (primarily physicians, infection control practitioners, and labs) who become aware of a patient with a notifiable disease/condition are required by law to report the case to the local/state health department and provide a limited amount of information about the patient. For some notifiable diseases/conditions, the health department more actively seeks out cases or collects information; for other diseases/conditions, the systems are relatively passive with little health department involvement. Legally, diseases are to be reported within a specified length of time (e.g., immediately, within a day, within seven days); however, these requirements are often not met.
· **Standard case definitions** are developed by the Council of State and Territorial Epidemiologists to enhance comparisons over time and in different geographic locations
· **Data Quality Procedures:** Dependent upon disease/health condition

Caveats
· Underestimate of the incidence of the disease/health condition due to under-detection, under-diagnosis, and under-reporting (tip of the iceberg)
· Inconsistent level of detection/reporting in different populations due to differences in access to health care, source of health care, and reporting effort
· Inaccurate reporting of some information (e.g., race/ethnicity)
Best Uses
· Examine trends in moderately severe disease (i.e., requiring a health care encounter but not particularly leading to hospitalization or death)
· Characterize high risk populations
· Compare local, state, and national trends
· Investigate spacial patterns and correlates (including outbreak identification)
· Monitor impact of intervention/prevention activities due to relatively short

incubation/latency periods for most notifiable diseases/conditions

Comprehensive Hospital Abstract Reporting System (CHARS):

Description of the System
· **Purpose:** Initially developed to monitor hospital rates; now used to examine trends in causes of hospitalization, establish statewide DRG weights, create hospital specific case mix indices, characterize access to and quality of health care, and monitor morbidity due to selected health conditions

· **Coverage:** Hospitalizations (i.e. inpatient stays) for all patients treated in state-licensed acute care hospitals in Washington, regardless of patient residence. A hospital is defined as any health care institution which is required to qualify for a license under RCW 70.41.020. CHARS does not cover private alcoholism hospitals, no fee hospitals, US military hospitals, US veterans administration (VA) hospitals, or Washington State psychiatric hospitals. For eligible hospitals, data are received for hospital units that are Medicare approved, including psychiatry, rehabilitation, and bone marrow units.

· **Years:** Collection of data began in mid-1984; data are unavailable for 1984 and are limited for 1985-86

· **Key Data Elements:** Hospital number, zip code, birthdate, age, sex, length of stay, discharge status, total charges, payer, principal and secondary diagnoses, principal and secondary procedures, physician, DRG and DRG relative weight, E-code

· **Reporting System:** Hospitals abstract information from the uniform bill (UB92), code diagnoses and procedures, and submit the information to the state contractor by tape, cartridge, or electronic file transfer 45 days following the end of the month.

· **Data Quality Procedures:** Data are edited by the state contractor through system program checks. On a quarterly basis, hospitals certify that the number of discharges and hospital charges are 95% correct. Independent evaluation studies are done by data users.

Caveats

· Unit of observation is hospitalizations not individuals
· Excludes emergency room visits, outpatient surgery, outpatient clinics, military and VA hospitals (greatest impact on counties with military bases), free-standing surgeries, free standing mental health, substance abuse, and rehabilitation centers, birthing centers
· Does not contain data on Washington residents hospitalized outside Washington State and no reciprocal arrangements to share data between states (greatest impact in border communities)
· Changes in hospitalization practices might affect trends over time
· Residence based on zip codes (not counties)
· No race/ethnicity data collected
· Inaccurate reporting of some information

Best Uses
· Monitor hospitalizations due to relatively severe diseases (severe enough to warrant hospitalization consistently over time)
· Analyses on utilization of inpatient health care resources/medical care costs
· Analyses of source of payer
· Analyses on access to care by examining trends in preventable hospitalizations

Washington State Cancer Registry

Description of the System
· **Purpose:** "To accurately monitor the incidence of cancer in the state of Washington for the purposes of understanding, controlling, and reducing the occurrence of cancer in this state."

· **Coverage:** All residents of Washington State

· **Years:** Began in 1991

· **Key Data Elements:** Age, sex, race/ethnicity, residence, occupation, medical information including stage at diagnosis and treatment, health care provider, and treatment facility

· **Reporting System:** DOH contracts with two regional tumor registries (the Cancer Surveillance System of the Fred Hutchinson Cancer Research Center and the Eastern

Washington State Cancer Registry of the Blue Mountain Oncology Program) to identify and collect information on cancer cases in Washington State. Contractors obtain reports of cases from hospitals, pathology laboratories, ambulatory surgical centers, and physicians in their respective catchment areas. Contract staff complete data abstraction on reported cases or collect abstracts from hospital tumor registrars who complete them.

· **Data Quality Procedures:** DOH staff perform quality assurance activities including computer edits of the data to meet industry standards, review of a statistical sample of records to determine the accuracy of data items such as race/ethnicity, and hospital audits to determine the completeness of casefinding and accuracy of data abstraction/coding. DOH staff also provide training to hospital staff on data standards and appropriate methods for documenting data items.

Caveats
· May miss Washington residents with cancer who are diagnosed/treated out-of-state; however, data sharing agreements with Oregon and Idaho which began in 1996 will minimize the patients missed
· Differences in source of health care (and changes over time) may lead to varying levels of ascertainment
· Inaccurate reporting of some information (abstracted from medical record)
· Non-invasive stages not covered for some cancers (e.g., cervical cancer)
· Latency in disease development and delay in diagnosis limits monitoring impact of interventions

Best Uses
· Examine trends in invasive cancer incidence
· Compare cancer incidence to mortality trends
· Compare local, state, and national trends
· Compare population subgroups
· Study risk and protective factors
· Investigate spacial patterns and correlates

Pregnancy Risk Assessment Monitoring System (PRAMS)

Description of the System
· **Purpose:** To supplement vital records data and to generate state-specific data for planning and evaluating perinatal health programs.
· **Coverage:** New mothers (2-6 months postpartum) who are residents of Washington State
· **Years:** Began in 1993
· **Key Data Elements:** Age, race/ethnicity, education level, socioeconomic information, risky behaviors, health care during pregnancy, infant health care
· **Reporting System:** Participants are selected from birth certificate data using a stratified random sample based on race. The sample consists of about 600 new mothers for each racial/ethnic group (overall 5% of all Washington State births). Survey information is collected through a self-administered questionnaire with telephone follow-up for non-responders.
· **Data Quality Procedures:** Comparisons of data from birth certificates, the First Steps Database (Medicaid), and PRAMS have been undertaken

Caveats
· Response rate of 60-70%
· Collection of information 2-6 months after delivery may impact responses to more subjective questions and limits follow-up time for outcomes
· Self-reported information is not verified through other means
· Sample design prevents analysis of regional/county-specific data

Best Uses
· Monitor statewide trends in behavioral risks, health care, and pregnancy outcomes over time
· Correlate birth outcomes and health-related information, socioeconomic information, and behavioral risk/protective factors
· Examine impact of intervention/prevention programs

Topic	Deaths	CHARS	BRFSS	Notifiable Disease	Cancer Registry	Births	PRAMS	Other
General Health Status								
1. Total deaths	x							
2. Life Expectancy	x							
2. Self-Reported Health Status			x					
3. Hospitalization		x						
Major Risk/Protective Factors								
1. Tobacco Use and Exposure	x		x			x		
4. Alcohol and Drug Disorders			x				x	
3. Physical Inactivity			x					
4. Sexual Behavior							x	HIV/AIDS Knowledge and Behavior Survey
5. Nutrition			x				x	Fred Hutchinson data
6. Social Determinants of Health	x							
7. Environmental Health Risks			x					
Infectious Disease								
1. Childhood Immunization	x	x		x				School Retrospective Survey
2. Tuberculosis				x				
3. Hepatitis A	x	x		x				
4. Hepatitis B	x	x		x				
5. Meningococcal disease	x	x		x				
6. HIV/AIDS	x	x		x				HIV/AIDS Knowledge and Behavior Survey
7. Syphilis				x				
8. Gonorrhea				x				
9. Chlamydia				x				
Non-Infectious Disease								
1. Coronary Heart Disease	x	x						
2. Stroke	x	x						
3. Cholesterol screening			x					
4. Blood pressure screening			x					
5. All Cancer	x	x			x			
6. Lung Cancer	x	x	x		x			
7. Colorectal Cancer	x	x			x			
8. Female Breast Cancer	x	x	x		x			
9. Cervical Cancer	x	x	x		x			
10. Chronic Obstructive Pulmonary Disease	x	x						
11. Diabetes		x	x					
Violence and Injury								
1. Motor vehicle deaths	x	x						Traffic Safety Commission
2. Youth Suicide	x	x						
3. Hip Fractures Among People 65 and Older		x						
4. Head and Spinal Cord Injuries	x	x						
5. Homicide	x							
6. Child Abuse and Neglect								DSHS, Child Protective Services
7. Youth Arrests for Serious Violent Crime		x						ER visits; Arrests
Family and Individual Health								
1. Prenatal Care						x	x	
2. Adolescent Pregnancy						x		Abortion Reporting System
3. Unintended Pregnancy and Birth						x	x	Abortion Reporting System
4. Low Birth Weight						x		
5. Infant Mortality	x					x		

Environmental Health

	1	2	3	4	5	6	7	Source
1. Water system compliance								Drinking Water System
2. On-site sewage systems								Environmental Health MIS
3. Foodborne illness outbreaks				x				
4. Hazardous substance disease clusters								Cluster Investigations
5. Fatal occupational injuries								L&I, Fatal Occupational Cens.
6. Occupational Lead Poisoning & Overexp.								L&I, Occupational Lead Registry

Health Systems

	1	2	3	4	5	6	7	Source
1. Health insurance coverage								OFM, Rand Survey, '94
2. Access to essential health services			x					Health Personnel Resource Plan; Health Professional Licensing
3. Availability of primary health care								WA Hlth Coor. Coun, Rural Access to Medical Care, 1986
4. Emergency Medical Services Response								EMS & Trauma Registry
5. Health professional quality assurance								Disciplinary Reports
6. Health facilities and services quality assur.								Facilities & Services Licensing Database
8. Laboratory Proficiency Testing								Lab Quality Assurance